Advance care planning: have the conversation

Module 2: Advance care planning and the law in Victoria
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Healthcare settings: GP practice, hospital, aged care
Target skills: Knowledge of advance care planning law in Victoria, confidence, knowing your role
Time: 20-25 mins
2.1 Legal Glossary

2.1.1 Decision-making capacity

Decision-making capacity is a legal concept and is a recognised requirement for completing legal documents that prescribe future actions or decisions.

A patient with decision-making capacity makes their own decisions regarding medical treatment.

A patient is assumed to have decision-making capacity unless there is evidence to indicate otherwise.

A patient has decision-making capacity if they are able to do the following:

- understand the information relevant to the decision and the effect of the decision;
- retain that information to the extent necessary to make the decision;
- use or weigh that information as part of the process of making the decision; and
- communicate the decision and the person’s views and needs as to the decision in some way, including by speech, gestures or other means.

Decision-making capacity is decision specific and a person may have decision-making capacity in relation to some decisions but not others.

2.1.2 Consent

Informed consent is generally understood to mean the voluntary agreement by a patient to a proposed medical treatment, after proper and adequate information about the approach has been provided. This includes adequate information about the potential risks, benefits and alternative options.

Informed consent is generally required prior to carrying out medical treatment. Medical treatment may include any medical or surgical procedure, operation or examination and any prophylactic, palliative or rehabilitative care, normally carried out by, or under, the supervision of a registered practitioner.

A patient is incapable of giving consent if they do not have decision-making capacity in relation to the treatment.

2.1.3 Non-beneficial treatment

Non-beneficial treatment is extremely difficult to define, and is determined on a case by case basis.

A treatment may be non-beneficial if it:

- is highly unlikely to produce the desired effect; or
- may provide some short-term respite, but at a high cost and discomfort or further impairment of quality of life (Keon-Cohen 2013).

→ View Module 4.3.1 for information on why the term ‘futile’ should be avoided in conversations with patients, substitute decision makers and family members.
2.1.4 Medical treatment decision maker

A medical treatment decision maker is the person who may make decisions on behalf of the patient if the patient does not have decision-making capacity. The *Medical Treatment Planning and Decisions Act 2016* sets out how to identify a medical treatment decision maker. The medical treatment decision maker will be the first of the following who is reasonably available and willing to make the medical treatment decision:

- an appointed medical treatment decision maker (appointed in accordance with the *Medical Treatment Planning and Decisions Act 2016*).
- a guardian appointed by VCAT who was appointed to make medical treatment decisions.
- the first of the following with a close and continuing relationship (and if more than one person fits the description in a subparagraph, the eldest):
  - an adult child of the patient
  - a parent of the person
  - an adult sibling.

The medical treatment decision maker for a person under the age of 18 will always be their parent or guardian, or other person with parental responsibility.

→ View Module 7.5.1 for information on the medical treatment decision maker hierarchy

Medical treatment decision makers should be included by doctors in both the development and implementation of the patient’s advance care directive. It is the responsibility of the doctor to:

- assist the patient to choose the right person to be their medical treatment decision maker; and
- support the medical treatment decision maker to understand their role.

→ View Module 7 for information on how to communicate with different types of medical treatment decision makers when activating an advance care directive

2.1.5 Withdrawal and withholding of treatment

*Withdrawal of treatment*: is the removal of medical interventions that are burdensome and non-beneficial. It may result in the patient dying from their underlying condition.

*Withholding of treatment*: is the decision not to provide medical interventions that would artificially prolong life, which may result in the patient dying from the underlying disease or illness. (Department of Health 2012)
2.2 How to assess decision-making capacity

A patient is assumed to have decision-making capacity unless there is evidence to indicate otherwise. Assessment of capacity should take place as close as possible to the time at which the decision is required.

The assessment of capacity should focus on the way the decision is made, and not be a judgment about the decision itself. Patients who have decision-making capacity frequently refuse treatment, or fail to follow medical advice without their capacity being challenged. A patient should not be regarded as lacking capacity just because they are making a decision that is unwise or against what appears to be their best interests.

Section 4 of the Medical Treatment Planning and Decisions Act 2016 (Vic) outlines the meaning and assessment of decision making capacity.

In determining whether or not a patient has decision making capacity, doctors should have regard to the following:

- A patient may have decision making capacity for some matters and not others;
- If a patient does not have decision making capacity for a matter, it may be temporary and not permanent;
- It should not be assumed that a patient does not have decision making capacity for a matter on the basis of the patient’s appearance;
- It should not be assumed that a patient does not have decision making capacity for a matter merely because the patient makes a decision that is, in the opinion of others, unwise;
- A patient has decision making capacity for a matter if it is possible for the patient to make a decision in the matter with practical and appropriate support (which may include: using information or formats tailored to their particular needs, communicating and assisting a patient to communicate their decision, giving a patient additional time and discussing the matter with the patient, and using technology that alleviates the effects of their disability);
- Cognitive screening tests, such as the Mini Mental State Examination, are not measures of capacity.

To determine whether a patient has capacity, these steps should be followed (Department of Health 2014; Darzins et al. 2012):

- Ensure there is a valid trigger to justify a capacity assessment, e.g. the patient is demonstrating behaviour that puts themselves or others at risk, or making choices that seem inconsistent with their previously held values.
- Take reasonable steps to conduct the assessment at a time and in an environment in which the patient’s decision making capacity can be assessed most accurately.
- Engage the patient in the assessment process by seeking agreement and informing them about the process.
- Gather information about the triggers for the assessment, and information about the patient that can help inform an assessment of their decision making.
- Educate the patient about the relevant decisions to the extent necessary to ensure that ‘ignorance’ is not mistaken for ‘incapacity’.

Assess the patient’s capacity by diligently and thoroughly determining whether they understand and appreciate the decisions they face and consider the following questions:

- Can the patient understand the information relevant to the decision and the effect of the decision? (e.g. possible options, foreseeable outcomes of options). Information should be provided to the patient in a way that is appropriate to their circumstances (e.g. by using modified language, visual aids or other means).
- Can the patient retain the information to the extent necessary; and
- Can the patient use or weigh that information; and
- Can the patient communicate the decision and their views and needs as to the decision in some way (e.g. by speech, gestures or other means)?

- Take appropriate action based on the patient’s capacity results, including arranging for a medical treatment decision maker if necessary.
2.2.1 Reduced decision-making capacity

Despite reduced decision-making capacity, a patient may still have sufficient decision-making capacity for the specific decision. Alternatively, they may be able to contribute to making the decision by expressing their preferences, which the medical treatment decision maker must take into account.

It is the responsibility of the doctor to actively ensure that the patient is involved in medical treatment decision making as much as possible. Even though a patient may not have legal capacity to make a specific decision, they may still be able to express a view about what they want (Hope et al. 2003) to both doctors and their medical treatment decision maker.
2.3 Advance care directives

An advance care directive is a legal document that informs medical treatment decisions when a person does not have decision-making capacity. A person may consent to or refuse specific medical treatments in their advance care directive and they may include more general statements about their preferences and values.

There are two forms of statements that a person may include in their advance care directive – an instructional directive and a values directive.

- In an instructional directive, a person may either consent to or refuse a particular medical treatment. If the person subsequently does not have capacity to make a decision about that treatment, the instructional directive will apply as though the person has consented to or refused the treatment.
- In a values directive a person may make more general statements about their preferences and values and what matters to them. If there is not an instructional directive then the health practitioner will need to obtain consent from a medical treatment decision maker to provide treatment. The medical treatment decision maker must consider a values directive.

2.3.1 Limitations of an advance care directive

An advance care directive cannot contain any statement that would require an unlawful act to be performed or that would require a doctor to breach a code of conduct or professional standards. If an advance care directive contains such statements, these statements are void and have no effect, but the remainder of the advance care directive remains valid.

Consent to a specific medical treatment in an advance care directive also does not require a doctor to provide that treatment. It remains the responsibility of the doctor to determine which medical treatment is appropriate to offer.

2.3.2 Requirements to be legally binding

The Medical Treatment Planning and Decisions Act 2016 (Vic) states that for an advance care directive to be valid and legally binding, it must meet the following requirements:

- the patient has decision making capacity in relation to each statement in their advance care directive;
- the patient understands the nature and effect of each statement in their advance care directive;
- the advance care directive must:
  - be in English;
  - include the full name, date of birth, and address of the person giving it;
  - be signed by the person giving it (or by another person at their direction);
- the advance care directive must be witnessed by a medical practitioner and another person.

The Department of Health and Human Services has developed a standard form advance care directive that may be used.

2.3.3 When can an advance care directive be cancelled?

An advance care directive may be amended or revoked by complying with the formal requirements listed above for making an advance care directive. An advance care directive will also be automatically revoked by any subsequent advance care directive.
2.4 Legal liability

- Generally, a doctor cannot provide medical treatment without consent (except in an emergency). A doctor may face liability for a failure to obtain consent in accordance with the Medical Treatment Planning and Decisions Act 2016 when providing medical treatment to a patient without decision-making capacity.

- If a doctor is proposing to provide medical treatment to a person who does not have decision-making capacity in relation to that treatment, they must make reasonable efforts in the circumstances to locate an advance care directive and medical treatment decision maker. A failure to do so will constitute unprofessional conduct.

- If a doctor has not been able to locate an advance care directive or medical treatment decision maker, the doctor may administer routine treatment without consent. If the treatment is significant, the doctor can only administer the treatment with the consent of the Public Advocate.

- In the case of an instructional directive refusing a particular medical treatment, the doctor must withdraw or withhold that treatment. A failure to do so will constitute unprofessional conduct.

- In the case of an instructional directive consenting to a particular medical treatment, the doctor must provide that medical treatment if it is their opinion that it is clinically appropriate to do so. A failure to do so will constitute unprofessional conduct.

- If there is not a relevant instructional directive, the doctor must refer the decision to a medical treatment decision maker and consider any relevant values directive. A failure to do so will constitute unprofessional conduct.

- If a doctor, in good faith and without negligence, administers or does not administer medical treatment and believes on reasonable grounds that this was done in accordance with a valid advance care directive or medical treatment decision maker, they will not face criminal or civil liability.
2.5 What does it mean to act ‘in good faith’, in accordance with the preferences, values and personal and social wellbeing of the patient or ‘good medical practice’?

Acting in ‘good faith’
Acting with an honesty and sincerity of intention.

‘Good faith’ has its ordinary meaning of being well-intentioned or without malice (AHPRA Guidelines 2014).

Acting in accordance with the preferences, values and personal and social wellbeing of the patient
It is the responsibility of the medical treatment decision maker to make the decision they reasonably believe the patient would have made if they had decision-making capacity.

The Medical Treatment Planning and Decisions Act 2016 provides a staged approach for determining the decision the patient would have made. This requires the medical treatment decision maker to do the following:

- first, consider any valid and relevant values directive;
- next consider any other relevant preferences that the person has expressed and the circumstances in which those preferences were expressed; and
- if the medical treatment decision maker is unable to identify any relevant preferences, give consideration to the person’s values, whether expressed by the patient or inferred from their life.

The medical treatment decision maker must also consider:
- the likely effects and consequences of the medical treatment, including the likely effectiveness of the medical treatment, and whether these are consistent with the person’s preferences or values; and
- whether there are any alternatives, including refusing medical treatment, that would be more consistent with the person’s preferences and values.

If the medical treatment decision maker cannot identify any relevant preferences or values, they must make a decision that promotes the patient’s personal and social wellbeing, having regard to the need to respect the person’s individuality.

Acting in ‘good medical practice’
Doctors have a duty to make the care of patients their first concern and to practise medicine safely and effectively.

They must be ethical and trustworthy.

Doctors have a responsibility to protect and promote the health of individuals and the community. Good medical practice is patient-centred. It involves doctors understanding that each patient is unique, and working in partnership with their patients, adapting what they do to address the needs and reasonable expectations of each patient. This includes cultural awareness: being aware of their own culture and beliefs and respectful of the beliefs and cultures of others, recognising that these cultural differences may impact on the doctor–patient relationship and on the delivery of health services (AMC Good Medical Practice).